

Practicalities if you are a young person with lymphoma

This information is about some of the practicalities of living with lymphoma if you are teenager or young adult aged up to 24 years old.

There is a lot of information on this page. You might want to read it in chunks. You can use the links under 'On this page' to help you navigate to the parts that are most relevant to you.

We have separate information about **lymphoma in young people**, which explains what lymphoma is and how it is treated.

On this page

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We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email information@lymphoma-action.org.uk.

What happens if I am diagnosed with lymphoma?

There's no right or wrong way to feel when you first find out that your child has lymphoma. Your reaction might include a **mixture of feelings**, including shock, fear, numbness and disbelief. Some people are relieved to get a diagnosis after having various investigations into what might be wrong.

Once lymphoma is confirmed, you might have further **tests and scans** to help your doctors find out as much as possible about your lymphoma and how it is affecting you.

A **multidisciplinary medical team** (MDT) of health and social care professionals work together to plan and provide the **best possible treatment for you**. You should be assigned a teenage and young adult (TYA) **key worker** – a member of your MDT who will be your main point of contact for any **questions or concerns you have**. Usually, this is a lymphoma or haematology **clinical nurse specialist**.

It can be challenging to **wait for test results**, and different people find different ways of coping. Our helpline team is here to **support you** and your family however you are feeling.

What treatment will I have?

Your medical team should talk to you and give you written information about the **type of lymphoma** you have. You should be involved in treatment discussions unless you are under 18 and have specifically asked not to be. They should offer opportunities to talk to them about your **treatment** options, possible **side effects** and **late effects of treatment** (health problems that can happen months or years after treatment).

Your medical team plan the best possible **treatment** for you based on factors such as the specific **type of lymphoma** you have, the **symptoms** you are experiencing, and your general health.

Before you can have treatment, the hospital needs written **consent**. If you are over 16, you can sign the consent form yourself. If you are under 16, it's likely that a parent or carer will also need to sign it. Regardless of your age, you would usually be encouraged to be a part of discussions about your treatment.

Make sure that you understand what treatment involves and about any possible **side effects** and **late effects** of treatment. You might want to ask about any possible long-term implications of having lymphoma treatment, such as about any effects on your **fertility**.

There can be a lot to take in and understand, which can be particularly difficult in times of heightened **stress** and anxiety. There might be times that you'd like information repeated or to be explained in a different way. Health professionals are used to this so don't hesitate to ask as many or as few questions as you want to. You could ask whoever is with you to make notes of the answers you get. We have a list of suggested **questions to ask about lymphoma** that you might find helpful.

Where will I be treated?

Young people with cancer can be treated in:

- A specialist children's cancer centre called a **Principal Treatment Centre (PTC)**, which is a hospital with specialist facilities for diagnosing and treating children and young people (aged 13 to 18) with lymphoma.
- A **teenage and young adult (TYA) designated hospital**, approved to treat teenagers and young adults (aged 19 to 24) with lymphoma as part of its adult cancer services. If you are treated in a TYA designated hospital, your care is overseen by specialists at a PTC.
- A teenage and young adult (TYA) unit, which is sometimes part of an adult hospital. These units are designed specifically for TYA and allow you to spend time with and get support from other young people.

You might have some of your treatment and care in one hospital and other parts of it at a different hospital. This is called 'joint' or 'shared' care.

You can read more about **cancer services for teenagers and young adults** on the NHS website.

If you're between 19 and 24, you might be able to decide, with your medical team, where to have your treatment. You might want to think about:

- the general **environment and facilities** of each option
- **how much time you are likely to spend in hospital**
- whether you'd like friends and family to visit often and, if so, how easy this would be for them.

I was given the option of moving to a hospital with a Principal Treatment Centre for teenagers and young adults. However, I decided to stay at the hospital I was diagnosed in for two reasons. Firstly, and most importantly, I felt confident in my doctor, but also it was far easier for me to get to. I was the youngest on the ward by far, but I really appreciated the banter and support from everyone.

Natalia, diagnosed with lymphoma at 20

Most of your treatment is likely to be given to you as an outpatient, which means that you can go home overnight.

Most people with lymphoma have to stay at hospital overnight sometimes, either for treatment or monitoring of **side effects**, such as serious or persistent **infections**. If you need to stay in hospital overnight, a family member might be able to stay with you.

If you need to go to hospital frequently and making these journeys is difficult, speak to your clinical nurse specialist or **hospital social worker**; it might be possible for them to help with making travel arrangements.

It's often possible to visit a hospital before treatment starts so that you can familiarise yourself with the environment and ask any **questions**. For example, you might like to find out about:

- facilities such as a TV, WiFi access, a common room and a kitchen.
- social and emotional support, for example through social activities, **social workers**, youth support workers, **counsellors** or psychologists.
- **visitor policies**, such as when visiting hours are and what visitors can and shouldn't bring.

You might find it helpful to write down any **questions** you have before your visit. You could talk these through with someone, such as a parent or carer, or a close friend.

How much time will I spend in hospital?

How often and for how long you go into hospital for depends on factors, including:

- your treatment schedule, including the **type** and dose
- times when your medical team needs to keep closer checks on you, such as, if you develop an **infection** that needs treatment, or experience **side effects of treatment** that need to be monitored.

Your medical team should be able to give you information about how much time you are likely to spend in hospital.

How can I look after myself?

Taking good care of yourself during and after treatment can help in your **physical and emotional recovery**. It can also help to prepare you for treatment, reduce the risk of **side effects**, and lower the likelihood of developing other illnesses in the future.

Healthy lifestyle factors include good **diet and nutrition**, doing **exercise** and **managing stress**.

Talk to your medical team for advice on **coping with any symptoms of lymphoma**. It's also important to tell them about any side effects of treatment you experience. They can help you to manage them and adjust your treatment plan if necessary.

Smoking

Smoking increases your risk of developing infections, especially in the lungs. If you are having treatment for lymphoma, the risk increases further. To limit the risk of damage to the lungs, it's particularly important not to smoke if you've had **radiotherapy** to the lungs. Some **chemotherapy** drugs used to treat lymphoma can also affect your lungs.

If you do smoke, stopping can reduce your risk of some of the possible late effects of chemotherapy and radiotherapy, such as other cancers, heart disease and stroke. The NHS website has **information and support to help you quit smoking**.

Recreational drugs

During treatment for lymphoma, your body is working hard to process treatment. Recreational drugs could have an effect on your lymphoma treatment and increase your risk of developing side effects, so it's important to let your medical team know if you take them. Your medical team can offer support to help you to reduce or stop your use of recreational drugs.

Even after treatment, leading a healthy lifestyle that is free from recreational drugs helps to put you in the best position to stay in good health.

The NHS website has information and signposts to **help with stopping recreational drugs**.

Further support

As well as your medical team, **our helpline team are here to support you** from diagnosis, through treatment and beyond. You might also be interested in our **Live your Life** self-management programme.

There are also many other **organisations that offer support and information dedicated to children and young people with cancer.**

Risk of infection

Lymphoma and its treatment can increase your risk of getting an infection. Some infections need treatment with antibiotics and a delay in getting this treatment can be serious.

Be aware of the signs and symptoms of infection and contact your medical team straightaway if you develop any.

Although you can't get rid of the risk of infection entirely, there are **steps you can take to help minimise it.**

Education and training

You are likely to need some time out of **education**, particularly when you are having and recovering from treatment.

Let your school, college or university know about the situation. Find out how they can support you in keeping up-to-date with work, as well as in any other aspects of school, college or university life.

You might also be able to access hospital teachers or home tutoring. Speak to your school and hospital to find out what is available to you. The government website has information about **illness and education**. Although it is intended for parents and carers of a child who is unwell, you might still find the information useful.

It might help to tell your school, college or university about your:

- lymphoma and treatment plan, including any side effects of treatment

- risk of infection – lymphoma and some treatments can increase the risk of infection for several months after treatment finishes. Ask them to let you know as soon as possible about any illnesses among the student community, particularly chickenpox, measles and shingles.

Your consultant or GP can write a letter to explain your situation. Your **TYA keyworker** or **social worker** can also support the communication between your hospital and your place of education.

If you are at university, tell your tutor what is going on. In general, universities are as flexible as possible. Your university handbook should include policies in case of illness.

Work

Most people need to take some time out of work during, and often for a little while after, **finishing treatment**.

If you are employed, speak to your line-manager or Human Resources (HR) department to find out how they can support you.

Your consultant or GP can write a letter to explain your situation. Your TYA keyworker or social worker can also support the communication between your hospital and your workplace.

By law, your employer cannot discriminate against you and should make reasonable adjustments to your working arrangements during your treatment and **recovery**. Under the **Equality Act 2010**, this applies forever, not just while you are having treatment or for a limited time after finishing. For example, if you get **cancer-related fatigue** after finishing treatment, and you feel a break or flexible working arrangements could help, your employer must consider your needs and agree to them. Alternatively, they should work with you to come to an alternative solution, unless there is a good business reason not to.

Think about how much information you want to give other people you work with. It can help to plan some things to say and what you feel comfortable with them knowing.

You might be interested in our information about day-to-day practicalities, which includes about **working if you are employed or self-employed** and **managing finances**.

Relationships, family and friends

Adjusting to a life with lymphoma can put pressure on your **relationships**.

You are likely to experience changes to some of your relationships, for example, with **parents, siblings, a partner, friends and acquaintances**. Some relationships might become strained as people don't know quite what to say or do. There can be awkwardness, tensions and misunderstandings. Other relationships might grow closer.

It might feel difficult to talk about how you feel because you think people are worried about you, or perhaps it's scary to talk about what's going on. Being honest about your feelings and finding ways of **communicating effectively** can be deeply beneficial to your relationships and emotional wellbeing. You might also want to get in touch with **our helpline team** for further support.

Your parents or carers

One of the relationships that lymphoma can have a particular impact on is the relationship between you and your parent/carer, even if you are now an adult yourself. For example, you might think they seem overprotective and controlling. They might not want you to go out with friends or to go to certain places like cinemas, clubs, busy shops or use public transport if your white blood cell count is low (**neutropenia**) and you are at greater risk of infection.

Talk to your parents if you feel uncomfortable with their approach. It might help to come to some agreements together, for example:

- I will ask for help if I'm tired if you can let me do some things for myself.
- You can let me go out with my friends if I agree to stay home if I feel unwell.
- I will take responsibility and call you for help with getting home if I start to feel unwell when I'm out.

Brothers and sisters

It can be difficult to deal with siblings at home while you are unwell and you might feel unsure of how to talk to each other about the situation. They might seem worried about you and overprotective. They might be envious of the attention you are getting or you might feel jealous of them being able to carry on with their lives and usual activities while you are unable to do all that you ordinarily would. If you talk to them, they might surprise you with their support.

Partners

If you are in a relationship, this is likely to be a tough time for both of you. Your partner may feel helpless and not know what to say or do. Talk to them about how you feel. Try to be honest about how you feel and what they could do to help you. Think about things you can do together 'away from your lymphoma' too.

Friends and acquaintances

It's up to you how much or how little you tell others about your health. Think about what information you're comfortable with sharing. You could then find a way to send updates without having to repeat conversations. For example, you could have a key contact who lets groups of friends know the news you would like them to, or you could send a group email. Social media can be a great way of updating lots of people all at once, though keep in mind that anything you post could remain online in the future.

After treatment

At the end of your treatment, your medical team will provide you with a written summary. This outlines the treatment you've had and the short-term and long-term side effects you might be at risk of developing. It also summarises your programme of **follow-up appointments**.

Finishing treatment is a time of adjustment and finding a 'new normal'. Although it can bring relief and a sense of celebration, some people find the end of treatment difficult, having felt well-supported by the regular interactions with their medical team. There is no right or wrong way to feel – try to be patient as you adjust.

Your medical team should support you in your **recovery from treatment**, and you should be offered **personalised care and support** that is suited to your individual needs. You might also find our information about **keeping well after treatment** useful.

Follow-up

After treatment, you will have **follow-up appointments**. Your medical team should tell you how regular and frequent these are and about any symptoms to look out for that you should contact them about between appointments. They should also talk to you about possible signs of late effects and what to do if you notice them.

Medical matters after treatment

Your medical team should give you information about any precautions you should take, now and in the future.

It's important that any health professionals treating you know that you have had lymphoma and what treatment you've had. You should be given this information written down so that you can carry it with you.

You might also need to carry a card with information if you:

- have had your spleen removed (**splenectomy**)
- have had treatment with **radiotherapy**
- have had treatment with **steroids**
- need **irradiated blood** if you ever need a blood transfusion.

This is so that anyone providing medical care to you in the future (including doctors, dentists and anaesthetists) can take any necessary precautions. This might include monitoring you more closely and, if appropriate, offering you a different treatment.

There are some general health and safety precautions you can take to help you stay well after lymphoma:

- **Limit damage to your skin from the sun.** Treatments such as chemotherapy and radiotherapy can have a lasting impact on your skin's sensitivity to sunlight. Exposure to UV radiation from the sun can also increase your risk of developing other cancers. Take care to avoid damage from the sun by covering your skin and using a high factor sun screen (SPF 50), particularly when UV rays are strong. Cancer Research UK has more information about **sun, UV and cancer**. The NHS website also has advice about **sun safety**.
- **Keep up-to-date with any vaccinations you need.** Ask your consultant for advice about vaccinations, including whether to have the **annual winter flu jab** and the **pneumococcal pneumonia vaccination**. You might also need to have some vaccines you had in childhood repeated. You might be advised to wait until at least a year after you finish your treatment to have some live vaccines.
- **Get advice from your medical team** before you **travel to another country**.
- **Some treatments for lymphoma can affect your heart.** If you get pregnant later in life, you might need a scan of your heart and to be monitored more closely during labour.

You can read more about medical matters after treatment in our [Young person's guide to lymphoma](#).

References

The full list of references for this page is available on our website. Alternatively, email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users

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